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ABSTRACT

This manual was written to empower and inform the members of community support programs in the state of Kansas. A community support group is defined as a supportive community of people which works together in partnership to help each other master the symptoms of mental illness and develop healthy and meaningful lives. The manual was designed to be used in relationship with fellow community members, especially with case managers, and was written in a question-and-answer format to give the user a basis from which to ask questions of his case manager, psychiatrist, or other helping professional. The manual is organized into several sections and questions and answers are given in the areas of: (1) mental illness; (2) treatment; (3) patient rights; (4) self-help; and (5) life style. Also included in the manual are a Personal Resource Guide to be completed by the user, a list of recommended reading, a bibliography, and a blank page for notes. (NB)

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THE INFORMATION MANUAL

A Guide For Members Of Community Support Programs In The State Of Kansas

The Johnson County Mental Health Center
Community Support Services

Spring 1986

By

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DEDICATED TO

The Members Of The Community Support Program
At The Johnson County Mental Health Center

We would like to thank the following community members and special friends of our community for their support in making this manual a reality:

Annette Garner for typing, proofing and organization

Matt Modricin, Ph.D. for support and guidance during
hard times

Sherry McGowan for belief and vision

and

Susan Ring for heart

PREFACE

This manual is written to empower and inform the members of community support programs in the state of Kansas. In accordance with our philosophy, it is designed to be used in relationship with fellow community members, especially case managers. We recommend, in this regard, that it be read and discussed with your case manager either individually or in a group.

This manual is written for everyone, both female and male. As custom dictates, however, the masculine pronoun "he" will be used throughout the text.

INTRODUCTION

The questions and answers that this manual offer are meant as friendly guideposts in an often unfamiliar area. All basics of community support programs in the state of Kansas are covered in depth with a positive flavor from the "heart" of the Johnson County Community.

Many people worked hard on this manual, drawing from life and learning. It must be said that the time went fast, as the enthusiasm and belief grew that a good thing was happening.

We feel it is the most compact gold mine of information you are going to find in the area of community support programs. We think the basics will last and hopefully, go with you like the touch of a friend, as you and your new found friends grow together.

Fare-thee-well,

Bob Richardson
February 1986

"The More Incoming The Light The Faster All Of Us Will Travel."
R. Waggoner

PHILOSOPHY AND FORMAT

The Philosophy: We believe that each one of us needs to belong to a supportive and loving community to be healthy. We also believe that every member of a community has a need and a right to accurate information about community knowledge as well as to have his voice heard. When we listen to each other and share information, then we begin to work together in fellowship and as partners to improve our lives and master our problems. We need each other. This manual is offered in the spirit of sharing the questions we all must ask in our attempt to master mental illness. We will need each other to find the answers.

The Format: The Information Manual is designed in a question and answer format. We chose this format to give you a basis from which to ask questions of your case manager, psychiatrist and other helping professionals. We hope that by asking these questions you will enter into an informed discussion with your "community's" staff members. When discussing these questions with, for example, your case manager, we suggest that you compare the answers you receive with the answers provided in this manual. Hopefully, by discussing with your case manager the information you gain, you will arrive at an agreement on how best to go about mastering your illness.

When using the manual keep in mind that no two situations are exactly alike. The issues that you may struggle with in an attempt to master your illness, will likely differ in some way from the issues of other community members. Consequently, some of the information provided in the manual may not be relevant to your personal situation. Moreover, it is unlikely that the manual will answer all the questions you may have. It should be used only as an information resource and guide. For additional information or specific information about your situation, consult your case manager, therapist or psychiatrist.

TABLE OF CONTENTS

Dedication	ii
Preface	iii
Introduction	iv
Philosophy and Format	v
Mental Illness	1
Treatment	10
Patient Rights	22
Self-Help	27
Life Style	42
Personal Resource Guide	48
Recommended Reading	51
Bibliography	52
Notes	55

Mental Illness

Q: What Is Mental Illness?

A: Mental Illness¹ is defined as a disease which affects a person's ability to think clearly and logically. It often involves such symptoms as hearing voices (auditory hallucinations), seeing things that don't really exist (visual hallucinations), having false beliefs (delusions) and behaving in confused and unusual ways. There are different types of mental illness with each type having its own particular set of symptoms.

Q: What Is Meant By The Term Emotional Disorder?

A: An emotional disorder (affective disorder) is a form of mental illness which primarily affects a person's mood. It is a problem with experiencing and expressing feelings. It can affect a person's ability to think logically, behave appropriately and communicate clearly. There are several types of emotional disorders, including severe depression, mania and manic-depression or bipolar disorder.

Q: Why Are Psychological Problems Sometimes Called Mental Illnesses?

A: An illness is simply an unhealthy condition which (1) can be identified by a recognizable set of symptoms or signs, (2) has a predictable course, and (3) usually worsens if it is not treated. A psychological problem or "set of symptoms" does not have to have an identified physiological cause to be called an illness, although many people believe that mental illness is caused by physiological (biochemical or structural) problems in a person's nervous system. This has yet, however, to be conclusively proven. Moreover, not all psychological problems should be viewed as illnesses, since they do not fulfill the three above mentioned criteria. Nevertheless, the different types of psychological problems discussed in this manual each have identifiable sets of symptoms, which usually follow a predictable and worsening course unless treated. Consequently, they are correctly called mental illnesses.

Q: What Is Psychosis?

A: Psychosis means being out of touch with reality. A person suffering from psychosis (being psychotic) may seem disorganized and confused about the time, the date, where he is and who he is. He may be unable to take good care of himself and fail to eat well, get enough sleep, keep clean and communicate effectively with others. He may suffer from hallucinations and delusions. In general, he has difficulty knowing what is real from what is unreal. People who have schizophrenia or serious emotional disorders may periodically suffer from psychosis as part of their illness.

¹ The term mental illness as used in this manual refers to disorders of mind, emotion, and behavior.

Q: In General, What Are The Symptoms Of Mental Illness?

A: The symptoms that may indicate mental illness can be arranged into four categories. These are: (1) problems in perception, (2) problems in thinking, (3) problems in behavior, and (4) problems in mood. A person who has a mental illness may experience problems in one or more of the four categories of symptoms. Symptoms of mental illness can also be viewed as negative (the loss of a previous ability or characteristic, such as motivation) or positive (the addition of a symptom, such as hallucinations). In general, so-called positive symptoms are more effectively treated than negative symptoms.

The primary symptom experienced in the category of perception is called a hallucination. A hallucination may involve hearing voices when no one is speaking, seeing things or people that aren't there and smelling imaginary odors. The primary symptom that characterizes a problem in thought is called a delusion or false belief. This means holding a belief that does not fit with the evidence or what we know to be true about reality. Problems in thinking may also involve symptoms of poor concentration and memory. Problems in behavior often include experiencing difficulty in making friends, communicating and appropriately expressing oneself, and following community rules, laws and customs that adults are expected to obey. Withdrawing from other people and poor hygiene and grooming are two examples of problems in behavior. Problems in mood which often characterize emotional disorders may include depression, nervousness, agitation and a false sense of emotional well-being (euphoria).

Caution should be used when determining whether or not a person suffers from symptoms of mental illness. A person experiencing these kinds of symptoms should be evaluated by a trained and licensed mental health professional.

Q: What Is Meant By The Phrase Chronic Mental Illness?

A: Having a chronic form of mental illness means that the person has experienced symptoms of the illness for at least a two year period of time. The term chronic is no longer being used, however, and has been replaced by the phrase long-term mental illness. In contrast, having an "acute" episode of mental illness means that the onset of the symptoms were sudden and severe and lasted for a relatively short period of time, usually for no longer than two weeks. A person suffering from a long-term mental illness may periodically suffer from acute episodes.

Q: What Types Of Mental Illness Are Treated At Community Support Programs?

A: In general, any long-term mental illness which seriously impairs a person's ability to function effectively in important areas of his life. Such areas include the ability to work and make a living, caring for oneself both physically and emotionally and being able to form and maintain normal social and family relationships. The most common types of mental illness which can seriously interfere with a person's life include schizophrenia, severe and recurrent depression, mania and bipolar disorder. These illnesses will be discussed in detail later in the manual.

Q: How Many People Have A Long-Term Mental Illness?

A: It has been estimated that 1.7 million to 2.4 million people have long-term mental illnesses in the United States.

Q: How Serious Are Mental Illnesses?

A: The seriousness of mental illness varies from person to person. It affects everyone differently. Symptoms often vary in type and severity. They can cause either a mild, moderate, or severe disruption in a person's ability to function effectively in his life. The symptoms may also occur only one time, periodically or on a long-term and ongoing basis. They can also fade or change over time. Consequently, the diagnosis is sometimes difficult to determine and treatment may change over the course of the illness. Whatever type and severity of the symptoms, they should always be evaluated by a mental health professional. Such a professional can advise you as to the type and seriousness of your illness and can recommend effective treatment for your particular set of symptoms.

Q: Is There Any Hope For A Person Who Has A Mental Illness?

A: Yes. There is hope. Although mental illness is a serious condition, we now have effective programs of treatment with which to control and reduce the symptoms. A person who successfully follows his treatment plan and works with his treatment team has a good chance of minimizing the impact of the illness on his life. At the same time, he can also improve and expand upon the areas of wellness in his life. These are the dual goals of treatment: to minimize the areas of illness and maximize the areas of wellness. Stated another way, your goal for treatment should be to create a healthy and happy life style in spite of your illness.

Q: Does Having A Mental Illness Affect Intelligence?

A: No. Having a mental illness should not be confused with having low intellectual abilities or being mentally retarded. Most people who have a mental illness, in fact, are average or above average in intelligence. Nevertheless, mental illness can interfere with a person's ability to effectively use his intelligence to perform tasks and attain goals.

Q: Why Did I Develop A Mental Illness?

A: Most of us ask ourselves "why" questions when we are confronted with serious problems or tragic situations that we can't explain. We seek, for example, to know the meaning and reason for the loss of a loved one. It makes little or no sense to us. There seems to be no reasonable explanation. This is normal. It is a part of grieving. It is part of our struggle to understand, find meaning and cope with the hard parts of being alive. Why questions, consequently, are properly the domain of philosophy and religion. Each person, then, must find his own answer to the question of why he developed a mental illness. Each person must give meaning to his own experience in life.

We do not know why you developed a mental illness. We can, however, help you discover how you developed the illness and what you can do about it. Questions of how it happened and what to do about it are properly the domain of science. Medicine, nursing, social work, rehabilitation and psychology are all disciplines that can help you answer these questions. That is also the purpose of this manual. The proper focus of treatment, then, is upon how to master your illness, although we too share your need to find answers to the question of why.

Q: What Is Schizophrenia?

A: Schizophrenia is a kind of mental illness. It is characterized by a recognizable set of symptoms, which can vary in type and severity from person to person. The symptoms can also occur in different combinations. Common symptoms include disturbances in perception (hallucinations), thinking (false beliefs, confusion, poor memory and concentration), emotions (problems in experiencing and expressing feelings), communication (disorganized or mixed up speech) and behavior (poor motivation and hygiene, slowness, and withdrawal from others).

Schizophrenia, like heart disease, cancer and sugar diabetes tends to run in families. It affects both sexes equally, although men commonly become ill two years earlier than women, usually around the age of twenty. Schizophrenia can occur in acute episodes or be of a long-term nature. It usually involves episodes of psychosis.

Q: What Causes Schizophrenia?

A: No one knows what causes schizophrenia, although several theories have been proposed to explain the symptoms of the illness. These theories can be arranged into four categories. The first category of theory suggests that schizophrenia develops in a person as a result of problems in his social environment. Social environment theories include the belief that schizophrenia is the result of problems in a person's relationship to his parents. A similar theory suggests that the illness is a result of communication problems in a person's family. Schizophrenia is thought to develop, consequently, as an unconscious survival response of the person to his parents and/or the confused communication in his family.

The second category of theory views schizophrenia as the result of biochemical malfunctions in a person's nervous system. The most popular theory in this category is called the dopamine hypothesis. Dopamine is a chemical in the brain which transmits messages between nerve cells. According to the dopamine hypothesis, too much dopamine between nerve cells causes various sections of the brain to malfunction. The portion of the brain thought to be most affected, in this regard, is the limbic system, which regulates certain aspects of personality and emotion. Too much dopamine in the limbic system is believed to result in emotional, perceptual, and personality problems. These "problems" are diagnosed as the symptoms of schizophrenia. It is thought that biochemical malfunctions in the brain may be "triggered" by stress and/or anxiety.

The third category of theory explains schizophrenia as the result of hereditary factors. In other words, people with schizophrenia have a genetic-hereditary predisposition to the illness. It runs in families. A person's chances of developing the illness increase, if one of his relatives has the disease. A person with a sibling or parent, for example, who has been diagnosed with schizophrenia has a ten times greater chance of developing the illness than the average person. Moreover, a person with an identical twin who has schizophrenia or whose parents both have the illness, has a 50/50 chance of developing the disease. As a result of this evidence, many researchers have concluded that genetic-hereditary factors predispose a person to the development of biochemical malfunctions or structural abnormalities in the brain. These malfunctions or abnormalities are believed to cause the symptoms of schizophrenia.

The fourth and final category of theory includes the possibility that schizophrenia may be a result of injuries to the nervous system. One popular idea in this category involves the hypothesis that schizophrenia is caused by a viral infection occurring in infancy.

The virus is thought to attack and then injure portions of the brain that regulate a person's emotions, personality, and perceptions. In turn, these injuries are thought to predispose the person to the development of schizophrenia later in life.

As stated earlier, no one knows what causes schizophrenia. In fact, many theorists believe that the symptoms of schizophrenia can have many different causes. In addition, some researchers suggest that schizophrenia may be the result of a blend of causes, such as having a genetic-hereditary predisposition to the illness in which biochemical malfunctioning in a person's nervous system is "triggered" by stress. It should be noted, that the most current and extensive research supports a biochemical and genetic-hereditary explanation of schizophrenia, with environmental factors such as stress triggering the illness and/or influencing its course of development.

For additional information and clarification, consult your psychiatrist, nurse or case manager.

Q: How Many People Have Schizophrenia?

A: It has been estimated that one in every 100 people in the United States will be diagnosed as having schizophrenia during their lifetime. Approximately one million people currently have a diagnosis of schizophrenia in the United States and approximately 30 percent of all hospital beds are occupied by people diagnosed as having schizophrenia. It is estimated that nine million people have schizophrenia worldwide, with more people being hospitalized with the illness in developed countries than for any other medical condition.

Q: Can A Person With Schizophrenia Suffer From Depression?

A: Yes. It is common for a person with schizophrenia to suffer from depression from time to time. This is normal and to be expected. Having a serious mental illness is sometimes depressing. It can affect every area of a person's life. It can make it difficult for a person to meet his needs and attain the goals he has set for himself. Depression may also be caused by biochemical problems in a person's nervous system. This type of depression is usually of a more severe nature and longer in duration. It can be effectively treated by medication. For any type of depression, psychotherapy and support from friends can also be helpful.

Q: What Is Meant By The Term Affective Disorder?

A: Affective disorder is another name for emotional disorder. Affective disorders are primarily characterized by a painful disorder in mood. They can also affect a person's behavior and perceptions as well as his ability to think clearly.

There are two principal classes of affective disorders. These are mania and depression. Anxiety is another type of psychiatric disorder, although for our purposes, we will not define it as a mental illness. It can and usually does, however, have a significant impact upon a person who suffers from either schizophrenia or depression. Anxiety, in this regard, is believed to heighten the symptoms of mental illness and may sometimes trigger an episode of psychosis. Consequently, anxiety is often an issue in the treatment and mastery of mental illness.

In general, depression can be defined as a disorder in mood, which is characterized by feelings of low physical energy and a poor sense of self-worth. In contrast, mania is characterized by a heightened sense of self-worth, an agitated or euphoric mood, and an increase in physical energy.

Anxiety, which can occur at either pole of emotion (depression and mania) can be described as a sense of worry or fear. It is feeling on edge and restless and is usually characterized by tension in the muscles of the body.

Affective disorders are the most common type of mental illness. Approximately ten to twenty percent of the people in the United States will experience a depression at some point in their lifetime. Mania, on the other hand, which may alternate with depression in some people, is a relatively rare disorder. Estimates indicate that it may affect only one percent of the population. Anxiety, on the other hand, can be said to affect everyone, although in most cases it does not seriously interfere with a person's ability to manage his life or meet his needs.

Q: What Is A Major Depression?

A: A major depression is a serious episode of mental illness characterized by feelings of inadequacy, sadness, guilt and hopelessness. A person suffering from a major depression may experience a loss of interest in previously enjoyable activities, a decreased or increased appetite and need for sleep, a lowered sex drive, difficulty concentrating, a loss of confidence and an overall sense of fatigue. In addition, he may at times experience suicidal thoughts and feelings.

In some cases, a major depressive episode may be accompanied by symptoms of psychosis, such as hallucinations and delusions. The person may also experience feelings of anxiety. Major depressive episodes may occur only once or recur several times in a person's life. To be diagnosed as a major depressive episode, the symptoms of the illness must occur nearly every day for at least a two week period of time.

Q: What Is Mania?

A: Mania is a type of mental illness which occurs in episodes. It tends to alternate with feelings of depression in a person diagnosed as having a bipolar disorder. Episodes of mania may sometimes be experienced, however, by a person who does not appear to suffer from episodes of depression. Mania is characterized by an elevated or irritable mood, talkativeness, racing thoughts, inflated self-esteem, physical restlessness, poor judgement, a decreased need for sleep and distractibility. The symptoms must occur for at least a one week period of time or result in the person's hospitalization before a diagnosis of manic episode will be made.

Q: What Is Meant By The Term Bipolar Disorder?

A: Bipolar disorder (manic-depression) is a type of mental illness. It is a disorder of emotion in which a person's mood cycles or swings between mania and depression. Mania and depression are the two "poles" or extremes of affect. Hence, the term bipolar. Bipolar disorder is thought to be at least one third as prevalent as schizophrenia, although this number is increasing due to more precise diagnostic techniques. These techniques allow mental health professionals to more accurately distinguish between bipolar disorder and schizophrenia, which in the past were often confused. In the manic phase of the illness the person may experience the symptoms of elation, euphoria, impulsiveness, poor judgement, excitability, agitation, restlessness, racing thoughts and a decreased need for sleep. In the depressive phase, the person may experience sadness, a decrease in appetite, anxiety, poor concentration and a general slowing down in activity and thought. At both poles of the illness, a person may experience the symptoms of psychosis. Although bipolar disorder usually includes the symptoms of both mania and depression, a few people experience only mania. Nevertheless, as a result of custom, these people continue to be diagnosed as suffering from a bipolar disorder.

Q: What Is Meant By The Term Schizoaffective Disorder?

A: Schizoaffective disorder involves symptoms of both schizophrenia and an affective illness. A person suffering from severe episodes of depression or mania, for example, while at the same time consistently experiencing delusions or hallucinations that often don't properly fit with his mood, may be diagnosed as having a schizoaffective illness. The person's delusions and/or hallucinations persist, in this regard, even when his mood improves.

Q: What Are The Causes Of Affective Disorders?

A: As with schizophrenia, the theories proposed to explain the symptoms of affective disorders can be arranged into different categories. In this case, the theories tend to fall into two categories. The first category of theory explains the symptoms of affective disorders (mania, depression and bipolar disorder) as maladaptive reactions to a person's environment. Depression, for example, may be viewed as feelings of anger which cannot be properly expressed. Consequently, when anger isn't expressed or supported, it may be turned inward (retroflected) or held in by the person. This turning in of anger against oneself is thought to result in depression. Mania, on the other hand, is thought to be a maladaptive response to feelings of grief, fear or shock. It is a way a person deals with overwhelming feelings. The person rushes into frantic activity, rather than dealing with and expressing his feelings in another way. Moreover, he appears to deny his feelings of grief, for example, to such an extent that he experiences its opposite - euphoria.

The second category of theory suggests a biochemical malfunction in a person's nervous system as an explanation for the cause of affective disorders. Depression is thought to be the result of a deficiency in certain chemical transmitters between nerve cells in the brain. Those chemical transmitters are called norepinephrine and serotonin. Mania, on the other hand, is thought to be due to an excess of norepinephrine. In fact, some researchers believe that depression and mania are not two separate illnesses. Instead, they suggest that mania and depression are two different forms of the same illness, which differ primarily in severity.

Affective disorders, like schizophrenia, tend to run in families. This suggests that in some cases a genetic-hereditary factor may predispose the person to the development of an affective disorder. Therefore, the development of a serious emotional illness may have a biological basis. Nevertheless, many researchers believe that episodes of emotional disorders are "triggered", like schizophrenia, by stress, anxiety, and a variety of environmental factors.

Such environmental factors might include physical illness, the loss of a loved one, problems in relationships or at work, an auto accident or a series of small irritations or misfortunes. Consequently, the inability to support, manage and properly express a feeling in reaction to an "environmental factor," may trigger a biochemical malfunction in a person who is genetically predisposed to the development of an affective disorder.

Treatment

Q: What Is A Community Support Program?

A: A community support program is ideally a supportive community of people which works together in partnership to help each other master the symptoms of mental illness and develop healthy and meaningful lives. This supportive community consists of people who have mental illness, their family members, friends and trained mental health professionals. The members of community support programs work together to provide and participate in a variety of mental health services. These services are usually linked to local mental health centers to which a person is referred following his discharge from a hospital. A person, upon entering a community support program, is offered a variety of services in which to participate. These services are designed to attend to the biological, psychological and social aspects of mental illness. This is called the biopsychosocial approach. The biological or medical part of a community support program usually consists of psychiatric, nursing and medication services. The psychological services usually include case management, psychotherapy, crisis intervention and group therapy. The mastery of the social aspects of mental illness usually involves a person's participation in education groups, activity therapy, skill development, recreation, and prevocational training. Consequently, a person is offered a range of opportunities and services that are directed towards improving every area of his life.

Q: What Am I Expected To Do Now That I Am A Member Of A Community Support Program?

A: You are expected to work with your case manager, the staff and other community members to learn about and master your illness. You are expected to work on developing a healthy lifestyle. In return, you will receive support, friendship, treatment, guidance, a place to belong and be heard, opportunities for growth and expression, fun, humor and love.

Q: How Long Should I Participate In A Community Support Program?

A: You should participate for as long as it takes you to learn about your illness and sufficiently master your symptoms. The length of time will vary with each person. Nevertheless, most members of community support programs find it helpful to have at least periodic mental health check-ups. In addition, many people increase their participation at times of stress. The most important idea is to know that you can belong as long as you find it helpful in developing and maintaining a healthy and happy life style.

Q: What Kinds Of Professionals Make Up A Treatment Team In A Community Support Program And What Are Their Responsibilities?

A: There are a variety of mental health professionals on a community support program team. These professionals are often trained in such disciplines as psychiatry, psychology, nursing, social work and rehabilitation. Most treatment teams consist of a psychiatrist, nurse, case manager, psychotherapist, and rehabilitation staff. Your case manager is the key person on your treatment team and will work with you to coordinate your participation in all of the community support program services.

The following information describes the general responsibilities of the professionals who may be involved in providing your treatment:

Psychiatrist

A physician specializing in the treatment of mental health problems. The psychiatrist is responsible for (1) diagnosing and evaluating your mental illness, (2) determining appropriate treatment, and (3) prescribing medications and monitoring the medical aspects of your illness.

Psychiatric Nurse

A nurse specializing in the treatment of mental health problems. A nurse in a community support program has a variety of responsibilities including (1) monitoring your medications, (2) arranging appointments and medication checks with the psychiatrist, (3) providing education about medications, mental illness and health-related issues, and (4) assisting in all aspects of your total physical health.

Case Manager

A mental health professional who has the primary responsibility for coordinating your treatment plan and linking you to the services you need. A case manager will meet with you on an individual basis throughout your treatment in the community support program. The case manager's responsibilities include, (1) assessment - helping you to identify your strengths and areas of need in coping with your illness, (2) planning - helping you set goals for developing a healthy life style, (3) designing a treatment plan - developing with you the ways in which you are going to achieve your goals and master the symptoms of your illness, (4) linking to services - working with you to identify and acquire the resources and services you may need to live in the community, and (5) support and problem-solving - through a partnership, your case manager will provide support to help you find ways of dealing with problems in daily living.

In addition, he will teach you how to cope with your illness in a healthy and constructive manner.

Psychotherapist

A state licensed mental health professional trained to conduct psychotherapy. Most psychotherapists have a Masters degree in psychology or clinical social work. The primary responsibilities of a psychotherapist are to (1) help you to clarify and understand the meaning, reasons and feelings behind your behavior, (2) provide support in your attempt to master your illness, (3) learn effective methods for reducing anxiety, and (4) help you to cope with, reduce or eliminate problematic behavior, thoughts and feelings that prevent you from attaining your goals.

Rehabilitation Staff

Generally, mental health professionals from rehabilitation and educational disciplines. The primary responsibility of rehabilitation staff is to teach social, daily living, self-care, and prevocational skills through the use of recreation and activity therapy, prevocational training and skill building groups.

Q: What Is An Assessment?

A: An assessment is the process of evaluating the type and severity of your symptoms and their impact upon your life. A psychiatrist may conduct an assessment of your illness by asking you questions about your symptoms, your past treatment, and your past and current abilities to meet your needs. This assessment might also include questions about your medical history, drug and alcohol use, vocational and daily living skills, and your relationships with family and friends. You may also be asked to obtain a complete physical examination from your family physician. In general, the purpose of a psychiatrist's assessment is to diagnose your illness and then to prescribe the most effective method for treating your symptoms.

Your case manager may also ask you to participate in an assessment of your illness. A case manager's assessment, however, may differ from a psychiatric assessment in its focus. In general, the major focus of a case manager's assessment is upon your ability to cope with the symptoms of your illness. This involves evaluating your ability to successfully develop a healthy life style while living in the community. The purpose of a case manager's assessment is to (1) determine your ability to successfully meet your needs, (2) identify the areas of skill in which you may need to improve in order to master the symptoms of your illness, and (3) identify your areas of strength which can be built upon to improve your life.

Q: What Is Meant By The Term Rehabilitation?

A: Rehabilitation means to restore to a state of health. This definition implies that a person has suffered from a state of ill health and through a process of rehabilitation, is made "whole" or well again. The entire treatment design in a community support program can be viewed as a part of a rehabilitation process through which a member of the program travels in his attempt to master his illness and establish a state of well-being. Consequently, some community support programs prefer to use the term rehabilitation rather than treatment.

Q: What Should I Do If I Disagree With My Treatment Or Rehabilitation Plan?

A: Treatment or rehabilitation plans should be developed in partnership with your case manager. You should generally agree upon (1) the areas of your life which need to be improved, (2) your goals, (3) the plan of action you will take to attain your goals, (4) which partner will be responsible for performing particular tasks in the plan, and (5) how long it should take. The overall goal of the plan should be the mastery of your illness and the establishment of a healthy lifestyle. Disagreement with your case manager may happen in any of the five areas of treatment planning. When you disagree with your case manager, first let him know what you disagree with and then how you would like it changed. Make sure you state your differences and wishes clearly. It is important that your case manager understands what you are saying. In a situation in which you feel that your case manager does not hear or understand you, tell him how you feel. Let him know that you do not feel understood. Sometimes, however, you will simply disagree. This is normal. We suggest that you take two steps in this case. First, try to negotiate. You give a little and he gives a little. Second, concentrate upon the areas in which you agree. Always work from your strengths. Disagreement, in this regard, does not mean a lack of caring or respect. In fact, it means the opposite. It means that you care enough to be honest and open with your partner. That honesty and openness is the strength of your partnership from which you will eventually arrive at a workable solution to the problems in your life. Don't give up. If you need help in your relationship with your case manager, do not hesitate to ask his permission to bring in another staff member. A third party can sometimes help negotiate your differences.

Q: What Information Should I Share With My Treatment Team?

A: All information given to your case manager, psychiatrist and other treatment team members is confidential. It cannot legally be shared with other people without your permission.

There are two exceptions: First, if you intend to harm yourself, and second, if you intend to or have harmed another person. In either case, the appropriate law enforcement and medical personnel will be notified. We believe, nevertheless, that it is best to first discuss any serious action you intend to take in your life and its possible consequences, before you make a final decision. We have found that by discussing the issue first, our community members eventually arrive at a decision that is healthy and satisfying both for themselves and other people.

Your treatment team will want to know about you in order to understand what issues you are dealing with and how to best help and support you. Consequently, they will need information about your history of wellness as well as your history of illness. They may ask questions about every area of your life that is affected by your illness in an attempt to help you. They want to understand. They may ask you about your feelings, thoughts, habits, relationships, activities, likes and dislikes, dreams and wishes, physical health, work history, housing, and living situation. They want to get to know you. They believe that knowledge is power and that the power of knowledge is needed in order to help you master your illness. Feel free to ask them to share their ideas and impressions about the information you have given them. It is a partnership and you need the power of knowledge, too.

Finally, it is also O.K. to say no. At times you may not feel comfortable in sharing information. Share what information you can with your treatment team. As you get to know them and hopefully, trust them, you may feel more comfortable in sharing information about yourself.

Q: How Will I Pay For My Treatment?

A: Most persons with long-term mental illness do not have private health insurance to pay for treatment or their insurance is inadequate to totally cover all of the expenses. The first step in dealing with payment for your treatment is to meet with your case manager to discuss your individual situation. Until you have acquired a regular set of benefits, your case manager can help you establish a reasonable fee and fee payment for your treatment.

General Assistance: General Assistance (Welfare) is provided through the Kansas Department of Social and Rehabilitation Services (SRS). Any person who is 18 years of age or older is eligible for these benefits if he has limited resources and is determined to be "mentally disabled" by a certified psychiatrist. You can obtain application forms from your local SRS office. Also, you should request a Medical Disability Statement Form for your psychiatrist to complete. If you need help filling out the forms, meet with your case manager. An SRS worker will set an appointment to meet with you to review your completed application. You should take a copy of your birth certificate and your Social Security card to the appointment.

The benefits that may be awarded include a monthly cash grant, a medical card to pay for treatment, and Food Stamps. In some areas, a case manager may also assist a person in applying for a "Specialized Living" grant. You must be participating in a treatment program in order to receive this increase in the monthly cash grant. All of these benefits can be obtained on a timely basis if the proper procedures are followed. A person who is having difficulty receiving these benefits should consult with his case manager.

Social Security Benefits: After applying for General Assistance a person may then want to apply for Social Security Benefits (SSI and/or SSDI) at the local Social Security Administration Office. Supplemental Security Income (SSI) is the most common source of income for people with mental illness. Social Security Disability Insurance (SSDI) is for people who are disabled and who have a significant work history. Both programs have been developed by the federal government to help blind, aged, and/or disabled people who are unable to financially support themselves. The person must be diagnosed as having a specific mental disorder that is expected to last at least twelve months and to result in an inability to work. Other criteria include difficulty in performing daily living skills, completing work tasks, and poor concentration. After receiving your application, a disability determination team will assess your eligibility. Since this process usually takes at least three months, you should first apply for General Assistance.

If you are ruled ineligible for Social Security Benefits an appeal can be filed. Before appealing, discuss what documentation is needed with your case manager and psychiatrist. A ruling on an appeal may take up to nine months.

A person who receives SSI and/or SSDI may also be eligible for additional assistance from a variety of programs, including Medicaid, Food Stamps, and some housing programs.

Q: Why Are Medications Used To Treat Problems In Perception, Thinking, And Emotion?

A: Medications are used to support a person in his attempt to master his illness. They are used to control and reduce the symptoms that interfere with a person's ability to meet his needs. They do not, unfortunately, cure mental illness. Nevertheless, they are helpful, since failure to take medications as prescribed is the number one reason people experience a relapse of symptoms and return to the hospital.

Medications are used to treat disturbances in perception, thinking, and emotion. They are prescribed, in this regard, to control symptoms such as hallucinations, which often interfere with a person's ability to think clearly.

They slow down racing thoughts, clear up confusion and illogical thinking, and reduce or eliminate "voices" and visual hallucinations. Medications are also used to reduce anxiety, improve a depressed mood, control mania, and minimize the mood swings experienced by a person who has a bipolar disorder.

Q: How Is Schizophrenia Treated?

A: We have found that a combination of five treatment approaches has been effective in helping our members master the symptoms of schizophrenia. These approaches are (1) taking medication (neuroleptics) to help control and reduce the symptoms, (2) obtaining education about the illness and how to develop a healthy life style in spite of it, (3) developing abilities such as cooking, money management, and job skills to help establish and maintain independent living, (4) participating in case management to obtain support and guidance, and (5) involvement in community and recreational activities to develop supportive friendships and social skills. In addition, participating in psychotherapy is sometimes recommended. Psychotherapy is designed to help a person understand and resolve confusing feelings, improve his ability to communicate more effectively, develop an understanding of his needs, increase positive behavior, help him with problems in relationships, improve his ability to cope with anxiety and reduce or eliminate negative and self-destructive behavior.

Q: What Are Neuroleptic Medications?

A: Neuroleptics are a type of medication designed to reduce the symptoms of psychosis. Consequently, they are sometimes called antipsychotics. They are believed to act by reducing the amount of the chemical messenger dopamine between nerve cells in the brain. As described earlier in this manual, too much dopamine between nerve cells in the limbic area of the brain is thought to result in hallucinations and delusional thinking. (Refer to the dopamine hypothesis.)

There are over twenty neuroleptics which are commonly used to treat the symptoms of schizophrenia. The most commonly prescribed neuroleptics are Haldol, Prolixin, Thorazine, Mellaril, Navane, and Stelazine. A particular neuroleptic is prescribed to a person based upon its ability to reduce his symptoms with a minimum amount of side effects. To find the particular neuroleptic which best serves a person's needs, a psychiatrist may try a number of medications until the most effective one is found.

After determining the most effective neuroleptic for a particular person, a psychiatrist must then decide upon the proper amount of medication to be prescribed. This amount will depend on many factors, including the person's height, weight, severity of symptoms, physical health, amount of body fat, and the severity of side effects arising as a result of taking the medication.

Consequently, the particular neuroleptic chosen and the quantity prescribed are tailored to the needs of each individual.

Q: Are Neuroleptic Medications Addictive?

A: No.

Q: What Are Some Common Side Effects Of Neuroleptic (Antipsychotic) Medications?

A: Reported side effects include faintness, nasal stuffiness, dry mouth, heart palpitations, and blurred vision. Drowsiness is the most commonly reported side effect, although this can also be a symptom of mental illness. Other reported medication side effects include restlessness, difficulty in focusing attention, lack of spontaneity, muscle spasms, missed menstrual periods in women, and sexual dysfunctions, involving problems with ejaculation and impotence in men. Medication-induced symptoms or side effects can usually be eliminated or reduced through a reduction or change in medication. Concerns about medication side effects should always be reported to and discussed with your psychiatrist, nurse and/or treatment team.

The most serious side effects that can occur from taking neuroleptic medications involve the development of symptoms called extrapyramidal and tardive dyskinesia. Extrapyramidal symptoms include the development of a stiffness in the person's body and face. Sometimes problems with walking in a relaxed and comfortable manner may also occur. Other reported symptoms include physical restlessness, feeling agitated, pacing (akathisia), rolling eye movements, and fine muscle tremors. The extent of extrapyramidal side effects produced by neuroleptics varies with each particular medication and the individual. They can usually be reduced or eliminated through the prescription of antiparkinson medications (Cogentin, Artane, Kemadrin).

The second type of serious side effect, tardive dyskinesia, involves the development of symptoms after neuroleptics have been used for a long period of time. These side effects occur in a relatively small number of people and involve involuntary movements of the person's mouth and face, as well as other parts of his body (neck, arms and hands). It is a disorder in movement. Tardive means persistent, in this regard, and dyskinesia means abnormal movements. When these side effects appear, a psychiatrist will likely choose one of at least three possible courses of treatment: (1) he may temporarily discontinue treatment with neuroleptics (a drug holiday), (2) he may reduce the amount of medication prescribed or (3) he may change to a neuroleptic medication which has fewer side effects.

In any case, extrapyramidal symptoms and tardive dyskinesia are serious side effects which should be discussed with your psychiatrist. They need attention. Please do not hesitate to discuss your concerns with your psychiatrist, nurse or case manager.

Q: How Is Depression Treated When It Occurs In A Person Who Has Schizophrenia?

A: It depends on the type and severity of the depression. In a case where the person feels depressed over his illness or a loss in his life, he may need only time, nurturing, support, and understanding. In other cases, an antidepressant medication may be prescribed, especially if the person is severely depressed, has trouble caring for himself and/or feels suicidal. Sometimes only a change in the type or dosage of a person's neuroleptic medication is needed to improve his mood.

Q: How Is Depression Treated?

A: There are three basic therapeutic approaches used to treat depression. These are: (1) medication, (2) electroconvulsive therapy, and (3) psychotherapy. In general, two types of medications are used to treat depression. These are tricyclic antidepressants, and monoamine-oxidase inhibitors. Tricyclic antidepressants are the most common type of medication prescribed to treat depression. The most popularly prescribed tricyclics are Tofranil, Elavil, Sinequan, Norpramin, and Avatyl. They are usually effective in their ability to reduce symptoms and improve a person's mood, with each medication having particular benefits and side effects. Tricyclics work by acting upon particular deficiencies in chemical messengers (neurotransmitters: serotonin and norepinephrine) between nerve cells in the brain. Different tricyclics act upon different types of chemical deficiencies, which may explain why a person responds better to one medication than another. This also suggests that there may be different types of depressive illness depending upon the type of chemical deficiency from which the person suffers. In addition to tricyclics, a new type of antidepressant medication has recently been developed. These are called tetracyclics. They are similar to tricyclics in their ability to reduce the symptoms of depression and improve a person's mood. Monoamine-oxidase inhibitors or MAOI's are another type of medication used to treat depression. They are usually prescribed when tricyclics have been ineffective. The most commonly prescribed MAOI's are Nardil and Parnate. They are rarely used in treatment, however, due to the widespread use and effectiveness of tricyclics.

Electroconvulsive therapy is one of the most effective methods used to treat depression. It consists of passing a small amount of electricity through the brain which results in a series of convulsions.

The person is quite safe during the procedure and is under the sedation of a barbituate. He is also in a state of deep relaxation due to taking a powerful medication which relaxes his muscles. Over a period of approximately three weeks, the average person will receive between eight and fifteen treatments. Each treatment lasts for approximately sixty seconds. Following a series of treatment, most people report experiencing a reduction in symptoms and an improvement in mood, although they may also feel confused and suffer from some loss in memory for a brief period of time. Electroconvulsive therapy is rarely used at present, due to media misinformation and the effectiveness of medications. Nevertheless, its use continues in certain cases in which medication proves to be ineffective and/or the person is at a serious risk for committing suicide.

Finally, psychotherapy is also used to treat depression when the symptoms are thought to be caused by a reaction to loss and/or an inability to effectively express certain intense and disturbing emotions, such as anger, hurt or sadness. Psychotherapy is also used in combination with medication, when it is felt that the person must first experience an improvement in mood before psychotherapy can be helpful. Psychotherapy, in this regard, can be described as a talking therapy, in which the person discovers and then effectively expresses certain troubling thoughts and feelings under the guidance of a therapist.

Q: Are Antidepressant Medications Addictive?

A: No, psychological and/or physical dependence is rare and unexpected.

Q: Do Antidepressant Medications Have Side Effects?

A: All medications have side effects, which vary from person to person. Antidepressant medications do have side effects, although they are usually mild in comparison with the suffering associated with depression. Common side effects include drowsiness, blurring of vision, dryness of mouth, constipation and light-headedness. All medication side effects should be reported to and discussed with your psychiatrist or nurse.

Q: How Is Mania Treated?

A: Mania is usually treated with a combination of medications. Lithium carbonate, a naturally occurring salt, is prescribed with a neuroleptic to either prevent, manage and/or reduce the symptoms of mania. Lithium may also be prescribed alone, when a neuroleptic is believed to be unnecessary. In addition, electroconvulsive therapy is used, although rarely, in cases in which lithium or a combination of lithium and a neuroleptic is ineffective.

Q: How Is Bipolar Disorder (Manic-Depression) Treated?

A: Bipolar disorder is generally treated with a combination of three therapeutic approaches. These are: (1) medication, (2) education, and (3) psychotherapy and/or rehabilitation. Bipolar disorder is often effectively treated with a medication known as lithium carbonate. Lithium is a naturally occurring salt which when taken tends to level out the mood swings experienced by a person with a bipolar disorder. It both reduces and prevents the symptoms of mania and the consequent mood swing into depression. Lithium is an effective medicine, although like all medications, it does have side effects. These include experiencing slight tremors in the hands, stomach upset, a metallic taste, and at times, feeling tired. A person must keep a certain level of lithium in his blood in order for it to work effectively, as well as to prevent a toxic reaction (overdose). Consequently, the person must have the level of lithium in his blood measured on a periodic basis. This is called taking a lithium level. In addition to lithium, people with bipolar disorder are sometimes prescribed neuroleptics to treat the symptoms of psychosis. Antidepressants are also sometimes prescribed.

A person who has been diagnosed as having a bipolar disorder may also find it helpful to participate in education groups, rehabilitation, and psychotherapy. Education will help a person understand his illness and guide him in his mastery of it. Rehabilitation will provide a person with the necessary skills to develop a healthy life style. Psychotherapy can provide a supportive relationship through which a person can learn to understand and express his emotions and thoughts in a satisfying and effective manner.

Q: How Are Schizoaffective Disorders Treated?

A: Schizoaffective disorders are usually treated with a combination of medications that are also used to treat schizophrenia (neuroleptics), depression (antidepressants), and bipolar disorders (lithium). This disorder is difficult to treat and consequently, several different combinations of medications may be tried before the symptoms can be reduced. In addition to medication, the person with a schizoaffective disorder is usually asked to participate in the other services provided in a community support program: case management, activity and recreation therapy, skill development, psychotherapy and prevocational services.

Q: After Treatment, Will My Abilities Return To Normal?

A: Mental illness usually affects every area of a person's life: feelings, thinking, behavior, social and family relationships, as well as a person's ability to learn to take care of himself, and to work.

In the past few years, great strides have been made in the treatment of mental illness. Researchers, mental health practitioners, patients and their families have pooled their knowledge, skills, wisdom, and resources in order to find an effective treatment approach to mental illness. We have found, in this regard, that by taking medication, developing self-care and vocational skills, and by participating in supportive and meaningful relationships with others, our members have been able to make significant gains in mastering the symptoms of their illness. Rarely, however, have we seen a person return to his exact previous level of functioning. Nevertheless, many people have not only regained former abilities, but have also developed new skills. In many ways, the impact of mental illness upon a person's life is similar to that of a serious physical illness, such as diabetes, cancer and heart disease. The person may no longer be able to function as he once did, but through developing new skills and abilities and by living in a healthy manner, he will likely live a happy, meaningful and satisfying life.

Q: Can Psychotherapy Help Me?

A: Yes, although it is extremely doubtful that it can significantly reduce or eliminate the symptoms of mental illness. In most cases, in fact, the person must also take medications in order to use the gifts that psychotherapy has to offer. Psychotherapy, in this regard, should have as its goal the development of self-understanding. A good psychotherapist can help you recognize and change for the better how you respond to and influence your environment. He can help you deal more effectively with the problems in your life.

Participating in psychotherapy means entering into a special trusting relationship with another person, who is trained to help you expand the areas of wellness in your life, while reducing the problem areas. He may help you accomplish this in several ways. In general, a psychotherapist will listen to you and attempt to understand your situation and how you have learned to cope. He may then share his understanding with you, give you homework, help you express yourself in a healing manner, and/or simply provide support. He will help you set goals for improving your life and then work with you to develop strategies to attain your goals. Overall, psychotherapy can provide you with self-understanding, a special and safe relationship, and an opportunity to express and explore your feelings, thoughts and behaviors. In short, psychotherapy can help you deal with yourself, other people and reality in a more effective and satisfying manner.

Patient Rights

Q: What Are My Rights As A Patient?

A: On October 7, 1980 the United States Congress enacted the Bill of Rights for patients receiving treatment in mental health facilities. We believe it is important that you know your rights in order for you to participate fully in the treatment of your mental illness. Such knowledge should only enhance your abilities to decide upon your choice of treatment. The following are the major points presented in this bill:

- (1) You have the right to appropriate treatment. This generally means that as much as possible, you should receive treatment which supports your personal liberties. The phrase most often used is "least restrictive environment." A facility may restrict such liberties, however, in order to comply with a court order or a requirement of the law.
- (2) You have the right to participate, as much as you are able, in the development of a written treatment plan. You may also participate in periodic treatment reviews and discharge planning with the staff. We encourage you to participate, ask questions, and offer your ideas. It is important for you to learn about your illness, understand why a particular type of treatment may be prescribed and be informed of any possible adverse effects that might occur as a result of receiving treatment.
- (3) You have the right to both refuse a particular method of treatment and be informed of alternative methods. From our experience, we have learned that it is best to make such decisions based upon factual information. Thoroughly explore all of your options with the staff. There are two exceptions when staff may override your decision:
 - a. an emergency when treatment is prescribed by a professional, and
 - b. court-ordered treatment.
- (4) You have the right to refuse to participate in any form of experimentation. If you wish to participate in a treatment experiment, you have the right to be informed of any possible hazards and benefits. You may also withdraw your written consent at any time.
- (5) You have the right to confidentiality of records. In most situations your records cannot be shared with any other person or facility without your written consent.

- (6) You have the right to assert grievances if you believe that your rights have been violated. The facility's grievance procedures can be explained to you by the staff.
- (7) You have the right to private phone conversations, mail, and visitors during scheduled hours while receiving treatment in an inpatient facility. For treatment purposes these rights may at times be restricted. These reasons must be explained to you and documented in your written treatment plan.
- (8) You have the right to talk with your lawyer or legal representative while receiving treatment in an inpatient facility. If you want your lawyer to have information regarding your diagnosis and treatment you must first sign a consent to release the requested information.

Q: What Happens When A Person Is Committed By A Court To A Hospital And How Can He Protect His Civil Rights?

A: When a person is ordered to go to a hospital by a court it is called an involuntary commitment. The purpose of an involuntary commitment is to evaluate and treat a person for dangerousness to himself and/or other people. Four criteria must be fulfilled before a person will be committed to a hospital. These are: (1) the person must be mentally ill, (2) he must be dangerous to himself and/or others, (3) he must be in need of treatment, and (4) he must refuse voluntary hospitalization.

Several steps must be taken before a person will be involuntarily committed. First, a petition must be filed with the District Attorney's Office, which requests that a hearing be held, in order to determine the person's need for hospitalization. The petitioner is usually a concerned family member, friend, law enforcement officer, or mental health professional. Second, a letter from a licensed psychiatrist must be received by the court, which states that the person is either a danger to himself and/or others and needs additional evaluation for treatment in an inpatient mental health facility (a hospital). Third, a lawyer or staff member from the District Attorney's Office must then discuss the situation with the petitioner and determine whether or not a commitment hearing is justifiable based upon the evidence presented. Fourth, a hearing to determine the necessity for involuntary commitment will be arranged to take place that same day or the following day, if the District Attorney's Office decides the evidence warrants this. Fifth, the person will then be notified of the time, date and place of the hearing. The person will be picked up and escorted to the hearing by the Sheriff's Department if he fails to comply with the court order. The person must attend the hearing. He may hire a lawyer to represent him.

A lawyer will be appointed by the court to protect the person's rights, however, if he is unable to afford one. Sixth, the involuntary commitment hearing is then held in probate court. The probate judge listens to the evidence, considers the psychiatrist's recommendations, and asks for reasons from both lawyers as to why the person should or should not be committed to a hospital for a psychiatric evaluation. The person may be asked to testify at this time. Under the lawyer's advice, the person may disagree with the petition or he may concur with the evidence and agree to voluntary hospitalization. In such a situation, the judge may agree to voluntary hospitalization and the petition will be dropped. Seventh, if the person does not agree to voluntary hospitalization the judge will review the evidence presented and then rule on the petition. He may rule: (a) that the person is not dangerous nor is he in need of treatment and that the involuntary commitment petition is denied, (b) that the person is not dangerous but does need treatment in which case he may recommend that the person attend counseling at a mental health center or with a private mental health professional or (c) in favor of the petition. This means that the judge finds the person to be a danger to himself or others and is in need of treatment. The judge will then order that the person obtain a psychiatric evaluation, which most commonly takes place at a state hospital. As a result, the person will be transported to the hospital for evaluation. After ten days another hearing will take place for the purpose of ruling upon the results of this evaluation. At that time, the judge will determine whether psychiatric treatment is necessary based upon the recommendations presented by the evaluating mental health professionals. When treatment is ruled by the judge to be necessary for the safety of the person and/or others, the person is returned for treatment to the evaluating hospital or another psychiatric treatment facility. Every 90 days thereafter, a review hearing is held to re-evaluate the person's need for continued treatment. Rarely does the person remain in the hospital for more than 90 days. Visits home during this period of time are usually permitted.

The following are some recommendations that have been helpful to people involved in involuntary commitment proceedings. They are:

- (1) Seek the counsel of a lawyer to insure that your rights are being protected.
- (2) Seek additional counsel with your lawyer, case manager, Legal Aid, or the American Civil Liberties Union, if you feel your rights are being violated.
- (3) Immediately notify your lawyer and case manager if you agree to voluntary hospitalization.

Finally, involuntary commitment to a hospital is usually unnecessary if you have arranged an agreement or contract for hospitalization with your case manager. We recommend that you develop this type of agreement with your treatment team. It will prevent the need for these painful proceedings. Please see the last question in the Self-Help Section of this manual for more details.

Q: What Is A Conservator?

- A: A conservator may be a relative, friend or interested party appointed by a court to manage the financial resources and property of a person who suffers from mental illness. A conservator is only appointed when the ill person has demonstrated over a long period of time an inability to manage his money and provide for his basic needs. A person who has been provided with a conservator, nevertheless, retains his right to make personal decisions and to conduct his life as he chooses on a day to day basis.

Conservatorship is only granted if it is in the best interest of the person who has a mental illness. There may be disagreement, however, over the need for a conservator in certain cases. A lawyer will be appointed to represent your needs and wishes if such a disagreement should arise. In addition, if you have a conservator, you may at times disagree with his decisions. You should discuss the matter with both your conservator and case manager in such a situation, in order to determine your best options.

Q: What Is A Guardian?

- A: A guardian may be a relative, friend, or interested person who is appointed by a court to manage an individual's personal affairs, property, financial resources, treatment, and general living decisions. A guardian, in other words, has more responsibility than does a conservator. There are rare situations when guardianship is necessary for a person with a mental illness. A guardian is usually only appointed for the purpose of protecting a person's financial resources and general state of well-being. Guardianship is the result of a legal court process which usually involves the person with a mental illness, his family, a psychiatrist, lawyers and a judge. It is important to remember that guardianship is used only as a last resort. A guardian is appointed only after the person has been unable to meet his needs over a long period of time due to his illness and is in danger of suffering from harm to his well-being and/or a serious loss of resources.

Occasionally, a person may disagree with the decisions of his guardian. In such a case, first discuss your viewpoint with your guardian in an attempt to work out a solution. When a solution cannot be reached, you should then consult with your case manager to discuss your options.

Self-help

Q: What Expectations Should I Have For Myself Following My Discharge From The Hospital?

A: You have recently survived a highly stressful experience. Consequently, you now need to feel safe and accepted. For this reason, the expectations that you have for yourself should be moderate. This includes following a simple daily schedule. Concentrate upon getting up each morning at a regular time, bathing every day, eating properly, attending your community support program, socializing with others, participating in recreational and leisure activities, and getting enough, but not too much, sleep.

As you begin to feel better as a result of developing and following a healthy daily routine, then the expectations that you have for yourself can increase. However, remember and follow these four rules of recovery: (1) take it easy, (2) give yourself time, (3) keep it simple, and (4) take one step at a time. You will know if you are moving too fast and working too hard when you begin to feel overwhelmed and/or experience an increase in symptoms. To prevent a relapse, we suggest that you meet with your case manager on a regular basis to discuss and review the expectations you have for yourself at any given point in your personal treatment program.

Q: What Are Some Reasonable Goals That I Can Have For Myself?

A: Reasonable goals will differ from person to person. In general, they will depend upon your abilities, the severity of your symptoms, the effectiveness of your treatment, and the amount of support and resources you can gather for yourself. We suggest that you set both short-term and long-term goals. Short-term goals might include applying for Social Security benefits and learning a new work skill. Long-term goals might include obtaining a job and getting married. Work with your case manager to set your goals, and then develop a reasonable time frame in which to attain them.

Q: In General, How Can I Best Cope With My Illness?

A: The following list contains several suggestions on how to successfully cope with mental illness. The suggestions are based upon the experiences of members from the Community Support Program of the Johnson County Mental Health Center.

- (1) Stay on your medications. Although they sometimes have unpleasant side effects, they do reduce symptoms and keep you out of the hospital.
- (2) Join a community support program where you can learn to master your illness in an atmosphere of friendship and support.

- (3) Develop a good, strong, and trusting relationship with your case manager. He is the person who will help you through both the good and bad times. He is your advocate and friend. He will give you straight information and support. His job is to help you master your illness while working with you to develop a satisfying and healthy life style.
- (4) Use plenty of humor. A person who can laugh, see the funny side of things, and tell good jokes is well on his way to mastering his illness. All in all, humor is just plain healthy. We welcome it.
- (5) Create and follow a daily routine. Get up at a regular time, participate in regular activities, perform daily tasks, eat well, keep clean, and work on getting into the "circulation" of everyday life.
- (6) Try to exercise on a regular basis. Run, bicycle, walk, or participate in recreational activities. Having a healthy body will make you feel better and improve your mood. It will also help you look better. It is a great boost to your self-esteem.
- (7) Avoid taking recreational drugs, including tobacco. Such drugs as marijuana, alcohol, and tobacco can damage your body. In addition, some people believe that certain drugs may trigger psychosis. Whatever the case, it is never wise to mix recreational drugs with your medications, since you may experience a negative and potentially harmful reaction.
- (8) Educate yourself about mental illness. You need to know as much as you can about your illness in order to master it. Knowledge is power.
- (9) Reward yourself for attaining your goals and accomplishments.
- (10) Participate in good, healthy and fun activities.
- (11) Develop some close friendships. Everybody needs friends. Providing us with concern and support, they share with us both the good and bad times in life. Friends accept what we have to give and bring meaning to our lives. They make it all worthwhile.
- (12) Find and develop a specific skill that you do particularly well. It might be in the area of music, sports, art, language, organization, mathematics, or communication. The point is that it is healthy to participate in a meaningful activity in which you can have your talent shine. It will make you feel good and be appreciated by others.

- (13) Avoid over stimulating people and environments. Too much stimulation and stress are thought to trigger the symptoms of mental illness.
- (14) Foster an attitude of hope in yourself and others by reading supportive books, watching inspirational movies, and forming relationships with positive people.

Q: How Can I Get More Control Over My Life?

A: The symptoms of mental illness can disrupt almost every area of a person's life. As a result, a person may feel helpless, angry, and afraid. He may feel out of control. He may also feel, consequently, that others are trying to control him. It is important and healthy then, for a person to establish control over his own life. In order to accomplish this, he will first need to get in control of the symptoms of his illness. This is most effectively and rapidly accomplished through taking medication. Next, he will need to learn about his illness, so that he can take effective action to maximize the areas of wellness in his life. He will also need to learn and develop skills to help him establish a healthy life style. Finally, he will need the support of others. This support can be received by participating in a community support program and by forming supportive relationships with friends and family members.

Q: In General, What Steps Can I Take To Prevent A Relapse Of My Illness?

A: You should understand that no matter how hard you try, your symptoms may worsen from time to time. You may then need to change or increase your medication and/or return to the hospital. You are not to blame when, and if, this happens. It is usually part of the normal course of mental illness. You can, however, reduce your chances for relapse by learning about your illness, monitoring your symptoms, avoiding over stimulating or stressful situations, following your personal treatment program, and working closely with your treatment team.

Q: What Are The Risks Of Using Recreational Drugs?

A: We recommend that people with mental illness avoid the use of recreational drugs. We do not take this position on moral grounds. It is not our place to say whether the use of recreational drugs is right or wrong, although the citizens of our state have determined many of them to be illegal. Instead, we caution you against the use of recreational drugs on medical grounds.

By the term recreational drugs, we mean the non-medical use of non-prescribed drugs for the purpose of obtaining pleasure and/or avoiding pain. Commonly used recreational drugs include marijuana, alcohol, hallucinogenics, amphetamines, barbituates, and cocaine. The primary reason to avoid the use of recreational drugs is that it may significantly increase your chance for suffering a relapse of your illness. It may result in your return to the hospital. In addition, by combining the use of recreational drugs with your medication, you may experience an unexpected and adverse reaction; your physical health may be threatened.

Despite these warnings, some members of community support programs continue to use recreational drugs. Consequently, those people who wish to use these drugs should do so in a non-addictive and non-abusive manner. We do not wish to imply, in this regard, any support for illicit drug use. Nevertheless, it happens and we wish to minimize the risks involved.

The following five characteristics are symptoms of abusive/addictive drug-taking behavior. A person who suffers from any one of these five symptoms is at risk of drug abuse and/or addiction. It should be said that a drug abuse/addiction is a serious and life-threatening illness in itself.

The Symptoms of Drug Abuse/Addiction

- (1) Taking the drug even when you don't really want to.
- (2) Any negative impact upon your ability to take care of yourself: working, grooming, eating, sleeping, managing money.
- (3) Taking the drug against medical advice; when it is a serious threat to your health.
- (4) Drug taking which seriously impairs or interferes with important relationships in your life.
- (5) When not taking the drug for a period of time results in symptoms of psychological and/or physical withdrawal.

In addition to the drugs already mentioned, we include the abusive/addictive use of caffeine and nicotine. These are the active ingredients in coffee and tobacco, respectively. The same symptoms of drug abuse/addiction apply to these commonly used and abused legal recreational drugs.

Their abuse can also result in a significant and negative impact upon your life.

Finally, we ask you to reflect upon and examine your use of recreational drugs. We suggest that you discuss the subject with a staff member whom you trust. It should be kept confidential. Upon reflection, if you should decide that you need help, then discuss the matter with your psychiatrist. Your case manager will help you. You will likely receive a concerned, caring and supportive response. For those members who feel satisfied with their use of recreational drugs, we continue to offer our concern, support, and love. Nevertheless, we do not agree with recreational drug use based on medical grounds, although we continue to be here for you.

Q: Can Recreational Drug Use Cause Mental Illness?

A: Maybe. The research conducted on this question is inconclusive. Nevertheless, many of our members believe that drug use triggered their first episode of mental illness. In addition, research indicates that an above average number of people with mental illness take drugs recreationally and/or abusively. Consequently, in many cases it is difficult to determine whether drug use triggered the symptoms or is itself a symptom of the illness.

Q: What Are "Voices" (Auditory Hallucinations) And What Can I Do About Them?

A: A hallucination is a disturbance in accurately perceiving reality. Hearing voices when no one is talking is one type of hallucination. It is the most common type of hallucination experienced by people who suffer from psychosis. The voices can take many forms. They may consist of a continuous dialogue or commentary or be a word or phrase that is repeated over and over. The voices may sound friendly and reassuring, commanding and directive, or abusive and insulting. They may be funny and give pleasure or feel disturbing and depressing. In any case, they make it difficult for a person to concentrate on tasks and pay attention to other people.

Taking your medication is probably the most effective action you can take to cope with the voices. These medications (neuroleptics) are designed to "blunt" or reduce the voices and consequently, make it easier for you to ignore them. In addition, with the help of your case manager or psychotherapist, you can learn to ignore the voices by developing a "non-listening attitude." This attitude will help you to dismiss them as a symptom of your illness. When you are unsure as to the reality of the voices, whether someone is really talking or not, please feel free to check it out with your case manager or another staff member.

Q: What Are Delusions and How Can I Best Deal With Them?

A: Delusions are false beliefs. They are beliefs that neither fit with the evidence nor what we know to be true about reality. They are not simply a difference of opinion. In general, a delusion is not believed by most people and seems to be true only to the person who holds it. Delusions usually fall into three categories. First, there is the type of delusion in which the person believes that he has special powers or is an important historical figure. Second, there is the type of delusion in which the person believes that others are trying to hurt him, although this is clearly not the case. Finally, there is the type of delusion in which the person believes that his body has been changed or injured in some manner, although no symptoms or changes in his body can be identified.

The most effective way in which to handle delusions is to take your medication. Neuroleptics tend to clear up thinking and make it easier for you to sort out what is true from what is false. In addition, check out your beliefs with a person whom you trust, preferably your case manager. He should be able to tell you if you are experiencing a delusion. This is called a "reality check." In a situation in which your case manager cannot determine if what you believe is delusional, he will then help you to arrive at the reality of the matter by collecting and sorting through the evidence. Finally, it is usually best to keep delusional thinking to yourself, unless you are seeking a "reality check" from a staff member. It is best not to act as if other people share these beliefs, since they may not understand that you are suffering from a symptom of mental illness. Consequently, when you are unsure as to the validity of a belief, get a reality check from your case manager and, in general, play it safe by keeping the belief to yourself.

Q: What Should I Do When I Feel Like Avoiding Others?

A: Everyone withdraws from time to time, usually at times of stress or illness. It may be a way in which we attempt to protect, heal, and renew ourselves. The need to withdraw for a person who has mental illness, however, can become so severe that it begins to seriously interfere with his ability to maintain relationships and successfully meet his emotional, social, and physical needs. This is called isolating behavior. It may occur as a result of delusions, anxiety, or depression. Unfortunately, by isolating himself from others, a person creates too much distance between himself and every day reality, and therefore, he cannot check out the truth of his perceptions and thinking. This may result in the development of additional false beliefs and consequently, more isolating behavior.

There are four general strategies you can use to balance your need to withdraw with your need for relationships. First, take your medications and follow your treatment plan. By following this suggestion you should feel better able to cope with others. As a result, you will experience less need to withdraw. Second, create and follow a daily routine in which you have at least a moderate amount of contact with other people. This might include participating in a community support program sponsored activity. Third, establish at least three friendships with others whom you contact in person or by phone on a weekly basis. Seek friendships, in this regard, with those people whom you like and enjoy being around. Finally, reward yourself for the contact you make with others. After you call or visit a friend, give yourself some quiet time, do an activity, or treat yourself to your favorite food. You will deserve it.

Q: What Can I Do If I Am Having Trouble Talking To Others?

A: In general, we experience problems in talking with others for three reasons. These are: (1) feeling anxious, (2) not knowing what to say or how to act, and (3) not knowing how to effectively communicate our feelings and ideas. For the most part, being prepared, breathing deeply, and giving yourself plenty of permission to make mistakes will help lessen the anxiety you may sometimes feel. It is important not to judge yourself too harshly or to have too many expectations for yourself. Give yourself permission to make mistakes.

Another strategy to help you feel more relaxed in the company of others is to develop some questions that you can ask. You might ask people about their work, pets, hobbies, TV shows, movies or the music they enjoy. In addition, try to develop some topics you might feel comfortable discussing in order to bring them into the conversation. For help, try observing someone who has good conversational and social skills and practice modeling them. Conversational skills are difficult to master and so you will need to practice. Nevertheless, knowing how to show interest in others by asking friendly questions, while also sharing information about yourself, will help you establish the supportive relationships we all need. For additional help, join a community support program social skills training group and/or work with your case manager.

Q: What Should I Do If I Feel Like Hurting Myself?

A: First, notify a member of your treatment team. Share this feeling with someone you trust. You should not be alone in this feeling and you will need plenty of support to cope with it.

When you share the feeling of harming yourself with another person, you begin the process of healing your underlying feelings of hurt, anger and despair. In fact, feelings of hurting yourself often arise as a result of being unable to express troubling and painful emotions to another person. You consequently feel all alone, overwhelmed, hopeless, and don't know what to do to make things better.

Second, if you are all alone, feel out of control, and don't have anyone to help you, don't hurt yourself. Either call you local emergency line or go to a hospital emergency room. The staff at these facilities are trained to help you. Professionals understand that sometimes people feel so overwhelmed or depressed that they can't stop thinking about hurting themselves. They may help you by getting you to a safe place like a hospital, when it is necessary, where you will have time to sort through your feelings, explore your options, and find solutions to your problems.

In addition, if you feel extremely depressed and suicidal feelings are a symptom of your illness, you may then be prescribed an antidepressant medication or be asked to take an increased amount of your medication until the feelings pass. They do pass and so, it is extremely important to not act impulsively. Give your treatment team the chance to help you.

Q: What Should I Do When I Feel Angry?

A: Anger is usually a secondary feeling. This means that anger often arises in us as a response to another feeling we experience. The two primary feelings that usually underlie anger are fear and hurt. First, something happens to which we respond with either fear or hurt, and then, rather than continue to experience these two uncomfortable feelings, we move into anger. We then seem to forget or ignore our original feelings. Anger, in this regard, is an emotion that protects us from experiencing painful feelings while at the same time, it motivates us to protect ourselves from whatever we fear might harm us. In addition, anger can be viewed as a statement of caring. When something we care about is hurt or threatened then we get angry. We usually do not feel angry over something or at someone we don't value. Consequently, anger is important in that it alerts us to the potential harm of something we care about.

Anger, then, is not the problem. It should not be held in, denied or ignored. This is unhealthy. The problem arises as a result of our difficulty in expressing anger in an effective manner. We can use a three step communication approach to express anger effectively. First, reflect upon what possible feelings underlie your anger. This emotion will occur for a brief moment before you feel angry. Ask yourself whether you feel afraid or hurt.

After recognizing the underlying feeling, express it either silently to yourself or to the other person if you feel comfortable. The other person may or may not be able to tolerate and/or care about your response. When you feel that it is not in your best interest to reach out to the other person and share with them how you feel, then it is probably best to keep quiet and express your feelings to a safe friend at a later time. Second, after recognizing both your primary feeling, as well as your secondary feeling of anger, attempt to express them to the other person. Try to talk about them rather than act. You might say, for example, "I feel hurt and angry." Next, let the other person know what they did to hurt or scare you. For example, "John, I feel hurt and angry because you again interrupted me." Do not assume, however, that they intentionally meant to harm you. We all hurt others through being insensitive and/or unaware. When you express your perceptions and feelings to another person, you are asking them to help you heal and/or protect your relationship. You are also saying that your feelings matter and that it is your right to express them. Then give the person a chance to respond. Hopefully, by working with your feelings of anger in this manner, you will resolve the painful feelings of hurt and fear, while at the same time, deepen your relationship to yourself and the other person. Remember, this is an extremely difficult skill to master. You will need to practice. We believe, however, that learning to work with your anger rather than denying, ignoring, or acting upon it is a very worthwhile goal for which to strive.

Finally, there are times when your illness may interfere with your ability to effectively cope with your anger. You may feel out of control and need outside help. At such times, medication can help you reestablish control and you may need to temporarily increase the amount you take.

Q: What Should I Do If I Feel Violent?

A: People who have mental illness are rarely violent. In fact, most people who have a mental illness dislike expressions of aggressiveness or hostility. They prefer to avoid them. It is only when a person feels afraid and confused that he may strike out at others. A person who suffers from a paranoid delusion, for example, may believe that others are attempting to harm him in some way. He is not perceiving reality accurately and so may easily misinterpret the behaviors of others. Consequently, he may become threatening and violent in an attempt to protect himself. To prevent this type of misunderstanding, we suggest that you discuss paranoid and violent feelings with either your psychiatrist or case manager. Your goal is to accurately perceive reality, feel safe, and resolve any violent feelings and/or ideas that you may have.

In other words, seek out a "reality check" from someone you trust. When violent feelings and ideas persist, however, they may signal a relapse of your illness. In such cases, your medication should be increased or changed. You may also find it helpful to spend a brief period of time in the hospital.

Q: How Can I Tell The Difference Between A Religious And A Psychotic Experience Or Magical Thinking?

A: The confusion between mystical and psychotic experiences stems from our inability to test out their validity with the tools of reason. In general, we can test out the validity of our perceptions in two ways. First, we can determine whether other people share our perceptions and second, we can attempt to repeat the experience to see if it will occur again. Throughout history, people have struggled with the question of whether or not religious experiences were actually psychotic episodes. We believe that they are two separate and distinct experiences. Psychosis, in this regard, means being out of touch with reality, whereas religious experiences deepen our understanding and contact with the world. In addition, people who suffer from psychosis tend to have difficulty in dealing with everyday reality. Having a religious experience, on the other hand, usually improves a person's ability to cope with the world. In fact, saints and mystics have usually been able to handle everyday reality in a practical and constructive manner. Their religious beliefs improve their ability to care for themselves and others, rather than interfere with the quality of their life.

Another difference between psychotic and mystical experiences is the tendency for psychosis to last for several days and even years, while mystical experiences last for very brief moments, minutes and sometimes, although rarely, hours.

There is also an observable difference between religious beliefs that are based upon faith and those that are based upon magical thinking, which is a symptom of psychosis. Religious beliefs based upon faith, like mystical experiences, cannot be tested by science or with reason. They are a matter of faith, which means to hold a belief in something or an idea for which there is no proof.

Nevertheless, religious beliefs can be either mentally healthy or lead to poor mental health. Healthy religious beliefs are identified by the positive impact they have upon a person's life. They are characterized by bringing a person closer to other people, increasing trust, supporting a person's growth and freedom, deepening his sense of enjoyment in life, emphasizing love and improving self-esteem.

Religious beliefs which lead to poor mental health, on the other hand, tend to separate people, increase mistrust, limit freedom, decrease enjoyment, emphasize fear, and weaken a person's sense of self-esteem. Your treatment team's only concern, in this regard, is that your religious beliefs improve the quality of your life. They are not experts in religion, although they are experts in mental health. Consequently, for questions of religious faith, we suggest that you contact your minister; for questions involving mental health, we recommend that you consult your treatment team.

Q: How Can I Improve My Concentration?

A: Having mental illness may affect your ability to concentrate. You may sometimes find it difficult to read, follow directions, solve simple problems or perform everyday tasks, such as cooking, cleaning or balancing your checkbook. Consequently, at times you may be unable to satisfactorily meet your daily living needs. You may, for example, have problems holding a job.

The Prevocational class in our Community Support Program developed the following list of suggestions to help themselves improve their concentration:

- (1) Develop a daily routine and stick to it.
This means have a schedule of tasks you practice on a daily basis. Write them down: get up at 8:00 a.m., take shower, comb hair, put on deodorant, put on clean clothes, fix breakfast and eat, go to community support program, attend job training
- (2) Keep it simple! Break difficult tasks into small steps. Write these steps down if you find it helpful. To clean your bedroom, for example, you might first dust the furniture, then vacuum or sweep the floor, empty the trash and then make the bed.
- (3) Stay on your medications and follow your treatment plan. Your medication will help reduce the confusion you may sometimes feel. It will help clear up your thinking. Consequently, it will also help you concentrate. In addition, your treatment should also help you feel better, which in turn will give you more energy to work on improving your concentration skills. You can work on improving your concentration by participating in money management and job training, and activities such as cooking class and crafts.

- (4) Create or find an environment supportive of concentration. Your daily environment should be well-organized and simple. It should not be over stimulating, noisy or confusing. This should be the rule at home, at the community support program and at work. Briefly spend time in a noisy and confusing environment and then in a quiet, simple environment. Notice the difference. Notice how you feel.
- (5) Avoid street drugs and alcohol.
- (6) Practice concentrating. Practice reading a certain number of pages of a good book each day. Try to watch a television program to its end. Begin and finish a small puzzle or craft. All of these tasks can help you improve your concentration.
- (7) Change tasks when you feel tired. When you feel tired of reading, for example, switch to another task, such as cleaning your apartment, cooking a meal or watching a television program.
- (8) Use "reminder" words or phrases. Put up cards in key places with words or phrases such as "Concentrate," "Be Here Now," or "Pay Attention ", to remind you to practice concentrating.
- (9) Avoid daydreaming, fantasizing and listening to voices. We often use these to withdraw from over stimulating or difficult situations and painful feelings. It is a way of choosing not to concentrate.
- (10) Most importantly, value "here and now, everyday reality" over "psychotic reality." Even though everyday reality can be difficult and harsh, it can also bring joy and satisfaction to you. In any case, everyday reality must ultimately be confronted by each one of us. Try to make it your friend.

Q: How Can I Get Motivated When I Feel Tired, Bored And/Or Depressed?

A: Feeling "unmotivated" will happen from time to time. It may be a signal that you are pushing yourself too hard and need to try something new for awhile. Unfortunately, it may also be a symptom of your illness. Consequently, it is important that you attempt to stay active and be involved with other people. Your opposite choice is to withdraw and fail to develop new skills and abilities; if this happens for an extended period of time, you will fail in your attempt to master your illness.

The rule, in this matter, states that either you master your illness or it masters you. It is important then to remind yourself that you are dealing with a serious illness which you are attempting to master. This means that you have the essential task of learning how to cope with your symptoms on a daily basis. For this reason, you should develop and perform a healthy daily routine for which you receive support from other people. When you feel unmotivated, ask these people for help in getting you involved in either learning new skills or participating in fun and enjoyable activities.

Q: What Can I Do To Help My Family Understand Mental Illness?

A: As stated earlier, mental illness affects relationships. It will likely affect your family. Your family may feel confused, scared, or angry. They may not understand your symptoms and out of ignorance, may believe that you do not have an illness. They may at first disbelieve that you are experiencing hallucinations, for example, and ask you to simply "pull yourself together." They may believe that you have control over your symptoms when in reality, you do not. They may also believe that they in some way caused your illness. They may feel guilty and blame themselves.

You can primarily help your family in three ways. First, ask them to obtain some education about mental illness. Ask them to read the Family Information Manual, which is a companion volume to this handbook. They can also read the books listed in the bibliography for additional information. Ask your case manager for help.

Second, ask them to attend a family group for the relatives and friends of people who have mental illness. In the state of Kansas, these groups are sponsored by an organization called Families for Mental Health. Families for Mental Health belongs to a larger, nationwide organization called the National Alliance for the Mentally Ill. These organizations provide education and support to family members in an attempt to help them cope with the impact of mental illness, both on themselves and people they love. These organizations also lobby and educate government officials and politicians to help gather resources to support the fight against mental illness.

Third, you can help your family by following your treatment plan. They will feel better and can help you more when they see that you are trying to master the symptoms of your illness. You may want to share your treatment plan with them and let them know how they can help you. Do not expect them, however, to take control of your life, since it is your life and you are responsible for how you choose to live it.

They will be most helpful to you when they simply offer emotional support and understanding. It may be beneficial, in this regard, to ask your case manager to help you talk with your family. He can help your family identify what type of support is most helpful to you.

Q: How Will I Know If I Am Getting Sick Again?

A: Episodes of mental illness often recur in patterns. These patterns vary from person to person. A person may experience "hard times," for example, every winter or after making a significant change in his life. Developing episodes of mental illness often have warning signs and it is for this reason, that you should get to know the pattern of your illness as well as its symptoms. This is also the reason that you should develop and follow a healthy daily routine. Any significant change in your ability to follow your routine may signal an impending relapse. Warning bells should go off. In general, you should become concerned when you experience either an increase in symptoms or a decrease in your ability to perform tasks and take care of yourself.

To help recognize an impending relapse, you must first know your illness. You must listen to yourself and take your symptoms seriously. You can help yourself by creating a personal warning network. Ask your staff, friends and family members to alert you when they notice either an increase in your symptoms or a decline in your functioning. Listen to and reflect upon the information they give you. When you agree that the warning signals of a potential relapse exist, reach out and get help. In most cases, the early detection of these signals can be used to prevent a relapse. Your treatment team will recommend the necessary action you should take.

Q: What Prior Arrangements Should I Make With My Treatment Team If I Should Need To Be Hospitalized In The Future?

A: We recommend that you first select a person or persons on your treatment team that you trust, who will help you make the decision whether or not to go to the hospital. At times, as a result of your illness, you may not be able to make the decision and you can then rely on these people to make the decision for you. You should develop and sign a "treatment contract" with these people, which will detail what should happen and who will perform the different and necessary tasks. There is a chance, however, that you may sometime disagree with your team or family about the necessity of hospitalization and this contract can also identify a person or persons of your choice who will make the final decision.

In order for this contract to work, each person who signs it must agree to follow the recommendations of the person or persons you select. These people may include your psychiatrist, nurse, case manager, and/or psychotherapist. For legal and treatment reasons, this person should be a member of your treatment team.

Life Style

Q: What Is Meant By The Concept "Healthy Life Style"?

A: A healthy life style is a way of living which values satisfaction, enjoyment and happiness. It is a daily routine designed to maximize wellness and minimize illness. It is a balanced approach to living and involves every area of a person's life, including work, leisure, recreation, physical and mental health, spiritual issues and relationships. It is based upon a person's needs, wishes, abilities and values. A healthy life style is particularly important to a person with a long-term mental illness, since it tends to minimize his chance for experiencing a relapse.

The following suggestions are a few Do's and Don'ts to guide you in developing your life style:

DO ... follow a simple daily schedule or routine

eat well balanced meals

get enough sleep on a regular basis

get some exercise

socialize with friends

take your medications as prescribed

follow your treatment plan

bathe regularly and have a neat appearance

give yourself permission to laugh

DON'T live your day without a plan or routine

substitute junk food for good nutrition

sleep too much or too little

isolate yourself

stop taking your medication without a doctor's recommendation

neglect to follow your treatment plan

ignore your hygiene and physical appearance

take on too much too fast

ignore the signs of stress

Q: What Areas Of My Life Are Most Likely To Be Negatively Affected By My Illness?

A: Mental illness can affect every area of your life. You may experience problems in thinking, perceiving, feeling and behavior. These problems, in turn, may affect your ability to both take care of yourself and attain your goals. The areas of your life most likely to be negatively affected by mental illness are work, self-care, and social relationships.

Q: How Can A Community Support Program Help Me Develop A Healthy Life Style?

A: A community support program is a community of people who care about and support one another in their individual attempts to develop healthy life styles. This "community" of people provides its members with opportunities to develop skills, participate in recreational activities, learn about mental illness and to form satisfying and meaningful relationships. A trained staff is provided to help you set goals and develop a plan for attaining a healthy life style. They are there to provide you with support, guidance and feedback.

Q: What Living Arrangements Are Best For Me Following My Discharge From The Hospital?

A: Selecting where you will live after being discharged from the hospital is a major step to take in creating a healthy life style. It is important to decide what is the best living arrangement for you. Prior to discharge you should fully discuss your options with the hospital staff, your case manager and your family. When deciding, take into consideration the severity of your symptoms, your living skills, the variety of living situations available, your financial resources, family support, and your personal preferences. You may have numerous options ranging from a nursing home, group home, apartment, or possibly living with your family. In general, it is better to live independently from your relatives, although at times living with a supportive family can be very helpful. When making living arrangements always consider if it is safe, comfortable, clean and located near supports such as friends, family and your treatment team. It should also be located close to community resources, such as transportation, shopping, medical and mental health services, entertainment, and educational and work opportunities. The goal is to find an environment which will support you in mastering your illness while minimizing your chances for relapse.

Q: What Is The Best Living Arrangement For Me?

A: Following a period of initial adjustment into the community, you will be asked to develop with your case manager, a set of goals which will include creating a healthy, safe and supportive living environment. These goals should build on your strengths and minimize your weaknesses. Your living environment should include support for your personal needs, housing, friends, work, and meaningful and enjoyable activities. You will want to balance the time you spend alone (quiet zones) with the time you spend with other people in the community.

You will want to develop a familiar and fairly predictable living environment in order to decrease stress. Achieving a healthy, safe and supportive living environment will decrease your chance for relapse and enable you to have a more positive sense of community and well-being.

Q: Should I Return To Work Following My Discharge From The Hospital?

A: You should first give yourself time to rest. Remind yourself that you are recovering from a serious episode of illness. You will need time to assess your situation, set goals and develop a plan of action. You will also need time to develop a significant degree of mastery over your illness. It is quite possible, nevertheless, to eventually return to work, although you will usually have to overcome these obstacles. First, you will have to build your confidence. Most people who experience an episode of psychosis lose confidence in their abilities for a period of time. This is why it is essential that you attempt to develop new skills. This will build your sense of being a capable person and will therefore increase the confidence you have in yourself. Second, you may also have to work to improve your attention and concentration, which are two abilities that mental illness often affect. You can improve your concentration and attention by participating in recreational activities, skill building classes and prevocational training. Third, you will have to develop your prevocational skills. This means that through prevocational training, you will learn, for example, to improve your ability to handle stress, organize and manage your time, improve your concentration and attention, develop your work relationship skills, and learn to assess and complete tasks. In addition, when you are ready, you may also be given the opportunity to develop a marketable job skill through a referral to the Vocational Rehabilitation Services of Kansas. This agency will assign you a vocational counselor who will help you to develop a work skill and then attempt to place you in a job.

Whatever your situation and abilities, it is important for your mental health, to engage in some type of meaningful and constructive activity. Everyone needs to feel that he contributes to his community in some way. Consequently, if you cannot hold a full time job due to the symptoms of your illness, then attempt to work part time or participate in volunteer or training activities. Do what work you can, although do not expose yourself to an overwhelming amount of stress. Too much stress can trigger an episode of illness. Instead, find a comfortable level of work or activity in which to engage and then concentrate on mastering the skills necessary to satisfactorily perform that job. After you have accomplished this goal, then try to move on to more demanding work, if you have the agreement of your treatment team.

Remember to avoid too much stress and concentrate on taking one step at a time. You will eventually find the right level of work for you.

Finally, we have found that people usually fail in their jobs for one of two reasons. They either attempt to work before they are ready or they take a job that is too stressful or uncomfortable. They take the wrong job for them. Consequently, at the Johnson County Mental Health Center's Community Support Program we use a simple formula to remind our members how to attain successful employment. We believe that by being job ready and then working in a healthy and satisfying job, our members will eventually obtain the success they desire in their work.

Job Readiness + The Right Job = Job Success

Q: Should I Talk To Others About My Illness?

A: You may sometimes feel uncomfortable and guarded about discussing your illness with other people. There will be times, however, when you will want to tell your story and be heard. It is advisable, in this regard, to discuss certain upsetting parts of your illness with only your treatment team, since they understand mental illness. You may also want to discuss your illness with your family, so they can understand what is happening to you. This will help them support you in your attempt to develop a healthy life style. In addition, you may want to tell certain friends. They will let you know in subtle and direct ways whether or not they are comfortable and ready to hear about mental illness.

There are other people who may need to know limited information about your illness. Physicians and other medical professionals need to know that you have an illness and the medications you have been prescribed. Certain agencies, such as the Social Security Administration and the Social and Rehabilitation Services, will need to know specific information in order to assist you with benefits. Employers may also need to know a limited amount of information. If you have concerns about telling someone about your illness, first discuss it with your case manager.

The best advice is to use common sense, good judgement, and discretion when talking about your illness. Ask yourself if it is in your best interest to share this information.

Q: Should I Have Sexual Relationships?

A: Sex is a normal human need. We all have sexual feelings and desires. It is fine and hopefully enjoyable, for a person with a mental illness to be sexually involved with another person. It is an individual's choice based upon his values, morals and beliefs.

In considering what to do with your sexual feelings, you might want to first discuss the subject with a staff member whom you trust. It is important that you receive factual and nonjudgemental information. Before making a decision, however, be sure to consider the following guidelines:

- Accept your desire for sex. It is normal.
- Engage in sex with only other consenting adults.
- Never force a person to have sex with you.
- Choose a birth control method in order to prevent unwanted pregnancies.
- Express your sexual feelings privately.
- Protect yourself from sexually transmitted diseases.
- Never have sex when you feel uncomfortable.
- Discuss with your psychiatrist what impact your medications can have on both your sexual feelings and your ability to perform sexually.

Sexual feelings can be confusing. You may sometimes feel disinterested in sex while at other times, you may feel an intense desire for it. This is normal. Some people, however, become preoccupied with sex and this is a symptom of their illness. They may become so engaged in sexual activities and fantasy that it interferes with their ability to form positive nonsexual relationships with other people. This happens because having sex is a way of nurturing ourselves when we feel unhappy, anxious or lonely. Becoming sexually involved with another person can be an intense, anxiety producing experience. It can also be a very intimate way in which to demonstrate our love for another person. Consequently, take it slowly. Make sure you feel safe and comfortable before becoming sexually involved. Above all, give yourself and the other person understanding and support. And as always, a good sense of humor helps.

Q: Can I Get Married?

A: Ben Franklin said of marriage,

"Keep your eyes wide open before marriage and half closed afterwards."

This means marriage is an important decision that merits a great deal of exploration and consideration. Before making this decision, try to answer these four questions honestly: (1) Can I meet this person's needs?, (2) Do I want to meet this person's needs?, (3) Can this person meet my needs?, and (4) Does this person want to meet my needs? If you answered any one of these questions negatively, then marriage is probably not your best choice at this time.

There are also more practical matters to consider. These include issues of finance, relationships with relatives and agreement upon life style. Questions of life style, for example, involve deciding whether or not to have children. It is also important to know how to communicate and to be able to "fight" with each other without hurting the relationship. This is known as "fair fighting."

Marriage should be a wonderful and meaningful experience, but it can also be an extremely painful and disappointing realization, if you fail to heed Ben Franklin's advice. Look at the total situation and give yourself lots of time before making the final decision. Above all, make sure you love the other person.

Q: Can I Have Children?

A: This is an important life decision. It is advisable for you to discuss it with a person whom you trust. This person should be knowledgeable in the area of mental illness. Information that you should consider before making a decision includes the possibility that your children may be predisposed to developing a mental illness. In addition, you should assess your ability to adequately care and provide for a child. Areas to be considered include your finances, housing, emotional stability, as well as your ability to tolerate stress and care for yourself. Moreover, you should also know that while the child's mother is pregnant, she will be unable to continue taking her medications. As a consequence, she will likely experience an increase in symptoms and possibly suffer a relapse if she is mentally ill. Nevertheless, children can bring you much joy. The question is one of both value and practicality. We suggest that you answer it by asking yourself what is the most reasonable, healthy and loving thing to do. Above all, before making a decision, determine your ability to provide a stable, consistent, and healthy family life for a child for at least an eighteen year period of time.

Q: Besides A Community Support Program, Where Else Can I Obtain Help For Creating A Healthy Life Style?

A: In addition to obtaining accurate information about mental illness and participating in a community support program, you can also find help in your local community. Turn to the Resource Section of this manual and ask your case manager to help you complete it.

Personal Resource Guide

PERSONAL RESOURCE SHEET

I. Mental Health Center & Medical Services

Mental Health Center: _____

Address: _____

Telephone #: _____

Crisis Telephone #: _____

Case Manager:

_____ Tel. # _____

Psychotherapist:

_____ Tel. # _____

Psychiatrist:

_____ Tel. # _____

Medicine Clinic/Nurse:

_____ Tel. # _____

Physician:

_____ Tel. # _____

Pharmacy:

_____ Tel. # _____

Medications (update as needed)

Name of Medication	Amount	Time of Day Taken	Date Prescribed
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

II. Financial Assistance

Social and Rehabilitation
Services:

Worker: _____

Address: _____ Tel. # _____

Social Security Office:

Worker: _____

Address: _____ Tel. # _____

Unemployment Compensation: Worker: _____

Address: _____ Tel. # _____

Veterans Administration:

Worker: _____

Address: _____ Tel. # _____

Emergency Assistance:

Social and Rehabilitation Services Tel. # _____

Salvation Army Tel. # _____

Red Cross Tel. # _____

Catholic Charities Tel. # _____

Jewish Family Services Tel. # _____

Other: _____

_____ Tel. # _____

_____ Tel. # _____

III. Vocational Services

Vocational Counselor:

_____ Tel. # _____

Placement Specialist:

_____ Tel. # _____

Vocational Rehabilitation
Services:

Worker: _____

Address: _____ Tel. # _____

Employment Office:

Worker: _____

Address: _____ Tel. # _____

IV. Housing Services:

Housing Authority:

Address: _____ Tel. # _____

V. Transportation Services:

Taxi Service: Tel. # _____
Tel. # _____
Bus Service: Tel. # _____
Volunteer Ride Services: Tel. # _____
Tel. # _____

Other:
_____ Tel. # _____
_____ Tel. # _____

VI. Legal Services:

Legal Aid: Tel. # _____
Lawyer: Name: _____
Address: _____ Tel. # _____

VII. Support Groups & Clubs:

Name: _____
Address: _____ Tel. # _____
Name: _____
Address: _____ Tel. # _____
Name: _____
Address: _____ Tel. # _____

VIII. Additional Names & Numbers:

_____ Tel. # _____
_____ Tel. # _____
_____ Tel. # _____
_____ Tel. # _____
_____ Tel. # _____

Recommended Reading

RECOMMENDED READING

1. Is There No Place On Earth For Me?, by Susan Sheehan
2. On Our Own, by Judy Chamberlin
3. The Long Journey Home, by Carol Ferland
4. Too Much Anger, Too Many Tears, by Janet Gotkin
5. Wander, Wander, by Dix Neyer

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Notes